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# Baby Doe's New Guardians: Federal Policy Brings Nontreatment Decisions Out of Hiding

*Nor have we studied and perfected the means by which government may be put at the service of humanity, in safeguarding the health of the Nation, the health of its men and its women and its children, as well as their rights in the struggle for existence. This is no sentimental duty. The firm basis of government is justice, not pity. These are matters of justice.*<sup>1</sup>

## INTRODUCTION

The death of a six-day-old infant in April 1982<sup>2</sup> was the catalyst for a society-wide controversy over decisions regarding the fate of severely compromised newborns. The "Baby Doe"<sup>3</sup> controversy generated a great deal of philosophical,<sup>4</sup>

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<sup>1</sup> T.W. Wilson, *First Inaugural Address*, (March 4, 1913), quoted in UNESCO & UNIPUB, INC., *BIRTHRIGHT OF MAN* 357 (1969).

<sup>2</sup> The baby is known as "Infant Doe" to preserve anonymity of the family. See Comment, *Baby Doe Decisions: Modern Society's Sins of Omission*, 63 NEB. L. REV. 888, 889 n.2 (1984).

<sup>3</sup> "Baby Doe" refers to any severely compromised infant with birth defects. See *id.* at 899. "The child called 'Baby Doe' has lent his name to all babies whose lives are similarly at stake." *Id.*

<sup>4</sup> Ethicists' arguments range from justification of infanticide to reverence for all human life no matter what the cost. Somewhere in the middle lie those who believe that an ultimate decision on how far medicine morally must go to keep an infant alive is not required. They argue that the question is not what is the ultimate answer, but rather, who is most qualified to make the decision. The underlying assumption is that the parents are not always acting in the child's best interest and, therefore, deference to their decision is unwarranted. The important element is that an infant's disability should not determine whether treatment is given. The child's potential for independence has no place in a decision to provide treatment because the potential of any infant is unknown at birth. The only relevant factors to a decision should be the risk of treatment and the futility of treatments which will not correct all of the life-threatening conditions. Compare H. KUHE & P. SINGER, *SHOULD THE BABY LIVE?* (1985) (advocating humane ways of ending life) with Kravitz, *Rabbinic Comment: The Infant With Severe Anomalies:*

medical,<sup>5</sup> legal,<sup>6</sup> and political<sup>7</sup> dialogue about who should decide whether life-saving treatments will be given to severely compromised infants. Many people were outraged<sup>8</sup> when they learned that a Down's syndrome<sup>9</sup> child with a surgically correctable condition<sup>10</sup>

*Should Life-Saving Surgery be Performed?*, 51 MOUNT SINAI J. MED. 34 (1984) (discussing the moral duty to preserve life).

<sup>5</sup> The medical community was largely opposed to government intervention into the physician/patient relationship. See Strain, *The American Academy of Pediatrics Comments on the "Baby Doe II" Regulations*, 309 NEW ENG. J. MED. 443 (1983). Some doctors, however, wrote that physicians should adopt their own review mechanism even if the Baby Doe rules failed:

There can be little doubt that the majority of professionals involved in newborn intensive care strongly disagree with the present administration's views on how to ensure optimal care to handicapped and critically ill newborns. . . . Nevertheless, we would maintain that there is much to be said in favor of what the Baby Doe regulation has accomplished within the medical profession.

. . . .  
[This] regulation has markedly advanced interest in alternative advocacy processes, specifically the development of infant bioethical review committees . . . .

Johnson & Thompson, *The "Baby Doe" Rule: Is it All Bad?*, 73 PEDIATRICS 729, 729 (1984).

<sup>6</sup> See generally A. HOLDER, *LEGAL ISSUES IN PEDIATRICS & ADOLESCENT MEDICINE* 110-17 (1985) (excellent discussion of potential legal liabilities of doctors who care for critically ill children); Annas, *Baby Doe Redux: Doctors as Child Abusers*, HASTINGS CENTER L. REP., Oct. 1983, at 26 (criticizing Baby Doe regulations); ORNELL, *The Forgotten Rights of Defective Newborns*, 1 HEALTH MATRIX 59 (1983) (advocating an eight-step decision procedure to protect the rights of handicapped newborns); TURNBULL, *Fundamental Rights, Section 504, and Baby Doe*, 1983 MENTAL RETARDATION 218 (rejecting the proposition that parental authority should always be superior in treatment decisions).

<sup>7</sup> See Mnookin, *Two Puzzles*, 1984 ARIZ. ST. L.J. 667, 675-77.

<sup>8</sup> "Right-to-life groups, those concerned with human rights in general, and those involved with rights of the handicapped in particular, expressed strong disapproval." Comment, *supra* note 2, at 892 (footnotes omitted).

<sup>9</sup> Down's syndrome is a form of mental retardation occurring in approximately one out of 700 live births. The severity of the retardation cannot be determined at birth. Often the condition is accompanied by congenital heart defects and gastrointestinal blockage. The gastrointestinal physical defects are usually surgically correctable. See Comment, *supra* note 2, at 889-90 nn.3-4.

<sup>10</sup> Infant Doe was delivered by Dr. Walter Owens, an obstetrician with privileges at Bloomington Hospital. Dr. Paul Wenzler, a general practitioner who had been the family physician for the parents, was the infant's initial attending physician. Both Dr. Owens and Dr. Wenzler tentatively diagnosed Down's syndrome, and Dr. Wenzler requested a consultation from Dr. James Schaffer, a pediatrician at Bloomington Hospital, who agreed with the Down's syndrome diagnosis and also believed that the

was permitted to die because his parents decided to forego necessary life-saving treatment.<sup>11</sup> The White House responded<sup>12</sup> by directing the Secretary of Health and Human Services (HHS) to remind federally assisted hospitals that they are prohibited by

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infant had tracheoesophageal fistula, a developmental anomaly characterized by an abnormal connection between the trachea and the esophagus resulting in the inability of food and fluids to pass from the mouth to the stomach. Dr. Wenzler and Dr. Schaffer recommended that Infant Doe be transferred immediately to . . . the designated neonatal high risk center, where necessary surgery to correct the tracheoesophageal fistula could be performed. A fourth doctor, Dr. James Laughlin, also a pediatrician on staff at Bloomington Hospital, examined Infant Doe and agreed with the diagnosis already made. He expressly noted, however, "There is clinically no evidence of other congenital anomalies. Further work-up work will be necessary to confirm internal organ defects." He agreed with the recommendation of Dr. Wenzler and Dr. Schaffer that the infant be transferred immediately for surgery to correct the esophageal atresia.

Marzen v. United States Dep't. of Health and Human Serv's., 632 F. Supp. 785, 788 (N.D. Ill. 1986).

<sup>11</sup> See Comment, *supra* note 2, at 890-91.

<sup>12</sup> See *id.* at 892. On June 16, 1982, the following notice appeared in the Federal Register:

There has recently been heightened public concern about the adequacy of medical treatment of newborn infants with birth defects. Reports suggest that operable defects have sometimes not been treated, and instead infants have been allowed to die, because of the existence of a concurrent handicap, such as Down's syndrome.

. . . .

We recognize that recipients of federal financial assistance may not have full control over the treatment of handicapped patients when, for instance, parental consent has been refused. Nevertheless, a recipient may not aid or perpetuate discrimination by significantly assisting the discriminatory actions of another person or organization. . . .

In fulfilling its responsibilities, a federally assisted health care provider should review its conduct in the following areas to insure that it is not engaging in or facilitating discriminatory practices:

Counseling of parents should not discriminate by encouraging parents to make decisions which, if made by the health care provider, would be discriminatory under section 504.

Health care providers should not aid a decision by the infant's parents or guardian to withhold treatment or nourishment discriminatorily by allowing the infant to remain in the institution.

Health care providers are responsible for the conduct of physicians with respect to cases administered through their facilities.

The failure of a recipient of Federal financial assistance to comply with the requirements of section 504 subjects that recipient to possible termination of Federal assistance.

47 Fed. Reg. 26,027 (1982).

section 504 of the Rehabilitation Act of 1973<sup>13</sup> from discriminating against handicapped persons. Section 504 provides that "[n]o otherwise qualified handicapped individual in the United States . . . shall, solely by reason of his handicap, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance."<sup>14</sup>

The Secretary responded by promulgating a rule requiring federally assisted hospitals to post a sign in maternity and pediatric wards.<sup>15</sup> The sign warned providers that "failure to feed and care for handicapped infants . . . is prohibited by federal law."<sup>16</sup> The notice also provided the telephone number of the Handicapped Infant Hotline.<sup>17</sup> Hospitals and physicians immediately voiced opposition to the government's interference in treatment recommendations.<sup>18</sup>

The American Academy of Pediatrics brought suit to have the rule declared invalid.<sup>19</sup> In *American Academy of Pediatrics v. Heckler*,<sup>20</sup> the rule was declared invalid because it was not promulgated in accordance with the procedural requirements of the Administrative Procedure Act.<sup>21</sup>

Subsequently, the Secretary of HHS promulgated new rules.<sup>22</sup> These were challenged and ultimately reviewed by the United States Supreme Court in *Bowen v. American Hospital Association*.<sup>23</sup> Although the case was decided on administrative law grounds,<sup>24</sup> the Supreme Court noted that child welfare decisions

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<sup>13</sup> Rehabilitation Act of 1973, § 504, 29 U.S.C. § 794 (1982).

<sup>14</sup> *Id.*

<sup>15</sup> Interim Final Rule, 48 Fed. Reg. 9630, 9631 (1983).

<sup>16</sup> *Id.*

<sup>17</sup> *Id.*

<sup>18</sup> Mathieu, *The Baby Doe Controversy*, 1984 ARIZ. ST. L.J. 605, 607-11.

<sup>19</sup> *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D. D.C. 1983).

<sup>20</sup> *Id.*

<sup>21</sup> *Id.* at 401.

<sup>22</sup> 45 C.F.R. § 84.55 (1985).

<sup>23</sup> 106 S. Ct. 2101 (1986).

<sup>24</sup> The Supreme Court affirmed the lower court's finding that the challenged "Baby Doe" regulations were outside the statutory authority of § 504 of the Rehabilitation Act of 1973. *Id.* at 2123. Therefore, they were invalid under the Administrative Procedure Act, § 10, 5 U.S.C. § 706(2)(C) (1982).

traditionally have been made by parents and regulated by states.<sup>25</sup> Because the Court was unable to find that Congress intended for section 504 of the Rehabilitation Act of 1973<sup>26</sup> to cover medical treatment of handicapped infants, the challenged regulations were held invalid.<sup>27</sup>

While the courts were struggling to interpret the scope of section 504, Congress made a clear showing of its intent to protect the rights of handicapped newborns in the Child Abuse Amendments of 1984.<sup>28</sup> Because these amendments were not in issue in the *American Hospital Association* case,<sup>29</sup> clarification of the current federal policy regarding treatment of handicapped newborns is needed.

This Comment attempts to reconcile the conflicting messages from the Supreme Court<sup>30</sup> and Congress,<sup>31</sup> to define the impact of federal policy on the states' abuse laws,<sup>32</sup> and to explain the decisional model which now replaces the traditional model of deference to parents and non-intervention.<sup>33</sup> The new decisional model puts the duty to review cases of treatment withholding on state child welfare agencies.<sup>34</sup> These agencies will be required to seek court orders to override parental choice in cases where the infant has a life-threatening yet correctable condition.<sup>35</sup> This shift in the law is long overdue. It will undoubtedly be difficult for judges to order treatment of a child knowing that the child may be rejected by his or her natural parents. Requiring this decision, however, seems no more disturbing than sanctioning the parents' decision to allow their child to die.

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<sup>25</sup> *Id.* at 2113 n.13 (quoting REPORT OF THE PRESIDENT'S COMMISSION FOR THE STUDY OF ETHICAL PROBLEMS IN MEDICINE AND BIOMEDICAL AND BEHAVIORAL RESEARCH 212-14 (1983) (footnotes omitted)).

<sup>26</sup> See *supra* note 13.

<sup>27</sup> 106 S. Ct. at 2123.

<sup>28</sup> 42 U.S.C. §§ 5101-5103 (1982), as amended by 42 U.S.C. §§ 5101(b)(6)-(7), (c), (e); 5102(1)-(2); 5103(b)(2)(E), (I)-(K), (b)(3)-(4), (c)-(f) (Supp. III 1985).

<sup>29</sup> See 106 S. Ct. 2101.

<sup>30</sup> See *infra* notes 57-75 and accompanying text.

<sup>31</sup> See *infra* notes 77-84 and accompanying text.

<sup>32</sup> See *infra* notes 85-94 and accompanying text.

<sup>33</sup> See *infra* notes 101-116 and accompanying text.

<sup>34</sup> 45 C.F.R. § 1340.14(h) (1985).

<sup>35</sup> 45 C.F.R. § 1340.15(c)(4)(ii) (1985).

## I. FEDERAL INITIATIVES TO PROTECT "BABY DOE": TWO ATTEMPTS

### A. *Section 504 of the Rehabilitation Act of 1973*

One of the implementing regulations<sup>36</sup> under section 504 of the Rehabilitation Act of 1973<sup>37</sup> gives the Secretary of HHS access to records of hospitals receiving federal financial assistance to determine compliance with the Act.<sup>38</sup> In October, 1983, the Secretary learned that University Hospital of the State University of New York at Stony Brook was allegedly withholding treatment from a handicapped infant.<sup>39</sup> The Secretary "repeatedly requested that the University Hospital . . . provide the Department with access to all of Baby Jane Doe's medical records."<sup>40</sup> When the hospital refused to release the records, the Secretary brought an enforcement action in federal district court.<sup>41</sup> The court granted summary judgment for University Hospital on the grounds that the Secretary's authority to access records is limited to situations in which he can clearly demonstrate discriminatory action by the recipient hospital.<sup>42</sup> The court found that the failure to perform surgery was due to the lack of parental consent which by law prohibited the hospital from performing the surgery.<sup>43</sup> This decision was appealed to the Second Circuit.<sup>44</sup>

On appeal, the issue in *University Hospital* was the authority of the Secretary's request for patient records to determine whether or not the hospital was in compliance with section 504.<sup>45</sup> The

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<sup>36</sup> 45 C.F.R. § 80.6(c) (1982) (incorporated by 45 C.F.R. § 84.61 (1982)).

<sup>37</sup> 29 U.S.C. § 794 (1982).

<sup>38</sup> 45 C.F.R. § 80.6(c).

<sup>39</sup> *United States v. Univ. Hosp. of State Univ. of N.Y.*, 575 F. Supp. 607, 611 (1983).

<sup>40</sup> 575 F. Supp. at 611.

<sup>41</sup> *Id.*

<sup>42</sup> *Id.* at 614.

<sup>43</sup> *Id.*

<sup>44</sup> *United States v. University Hosp., State Univ. of N.Y. at Stony Brook*, 729 F.2d 144 (1984).

<sup>45</sup> 729 F.2d at 146. The Secretary was informed that the hospital may have been discriminatorily withholding treatment from an infant known as Jane Doe. *Id.* at 147. The Secretary requested access to the records under his general power to investigate to

court reviewed the legislative history of section 504 and found that Congress did not intend for it to apply to medical treatment decisions.<sup>46</sup> The court stated, "[W]e cannot presume that by enacting section 504, congress (sic) intended the federal government to enter the field of child care, which, as HHS has recently acknowledged, has traditionally been occupied by the states. . . . Had congress (sic) intended to displace state policy functions, it surely would have made that intention explicit."<sup>47</sup> The sweeping language of this opinion sounded the death knell for the final "Baby Doe" rules<sup>48</sup> which had been promulgated just six weeks earlier.<sup>49</sup>

The final "Baby Doe" rules were promulgated in January of 1984.<sup>50</sup> In a consolidated case, *American Hospital Association*

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insure compliance with § 504 under 45 C.F.R. § 80.6(e) as incorporated by 45 C.F.R. 84.61. *Id.* at 147-48. In the interim, the Secretary referred the complaint to the state protection agency for investigation which found no cause for intervention. *Id.* at 147. Prior to HHS involvement, a state action seeking a treatment order was brought by a private party on behalf of Infant Jane Doe. *Id.* at 146. The New York Court of Appeals held that the trial court had abused its discretion by allowing the individual to bring the action without referring the matter to the state protection agency. *Id.* at 147. (The New York Court of Appeals decision is *In re William E. Weber*, Guardian ad Litem for Baby Jane Doe v. Stony Brook Hosp. et. al., 456 N.E.2d 1186 (N.Y. 1983)).

<sup>46</sup> *Id.* at 154-60.

<sup>47</sup> *Id.* at 160.

<sup>48</sup> See *infra* note 50.

<sup>49</sup> The rules were published in January, 1984. The Second Circuit's opinion in *University Hospital* was decided February 23, 1984.

<sup>50</sup> 49 Fed. Reg. 1622 (1984) (codified at 45 C.F.R. § 84.55(a)-(f) (1984)). Section 84.55(a) encouraged hospitals to develop an Infant Care Review Committee [hereinafter ICRC]. These review committees, it was hoped, would develop policies which would insure that handicapped infants received appropriate treatment. Section 84.55(f) proposed a model ICRC which could be followed by those who established an ICRC. Because these were optional rules, they were not challenged in the subsequent litigation on this issue. See *infra* notes 52 & 57-70 and accompanying text. Sections 84.55(b)-(e) were mandatory and immediately challenged. *Id.* Section 84.55(b) required hospitals to post a sign warning that federal law prohibited discriminatory treatment of handicapped infants. The sign had to include the telephone number of the local protection agency and the department of Health and Human Services [hereinafter HHS]. The signs were to be posted where hospital personnel providing health care to infants could see them. Section 84.55(c) required state protection teams to establish review procedures for referrals of suspected medical neglect. Further, it required that state agencies require health care providers to report instances of suspected medical neglect. Section 84.55(d) gave HHS the authority to demand access to medical records at any time of the day or night. Section 84.55(e) dispenses with the requirement of § 80.8(d)(3) of giving notice before initiating an action to order compliance, where such action is necessary to protect the life of a handicapped infant.



*v. Heckler*,<sup>51</sup> both the American Hospital Association and the American Medical Association challenged the authority of the Secretary of HHS to promulgate these regulations under section 504 of the Rehabilitation Act of 1973.<sup>52</sup> Relying on the Second Circuit's decision in *United States v. University Hospital*,<sup>53</sup> the district court granted summary judgment for the American Hospital Association.<sup>54</sup> The court held that the final "Baby Doe" rules were "invalid, unlawful and must be set aside pursuant to the Administrative Procedure Act . . . because promulgated without statutory authority."<sup>55</sup>

*American Hospital Association* was appealed directly to the United States Supreme Court.<sup>56</sup> The Secretary also requested the Court to review the Second Circuit's decision in *University Hospital*.<sup>57</sup> The Supreme Court affirmed *American Hospital Association* in a somewhat confusing plurality opinion.<sup>58</sup> The dissent argued that the plurality failed to address the issue of whether the Secretary of HHS has any authority under section 504 of the Rehabilitation Act "to regulate treatment decisions concerning handicapped newborn infants."<sup>59</sup>

One possible conclusion generated by the plurality's affirmation of the court of appeals' decision is that the Secretary is enjoined from taking any action to investigate or regulate treatment decisions of handicapped newborns under section 504.<sup>60</sup> A close reading of the opinion, however, casts doubts on such an expansive interpretation.<sup>61</sup> The plurality specifically found that

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<sup>51</sup> 585 F. Supp. 541 (S.D.N.Y. 1984), *aff'd*, 106 S. Ct. 2101 (1986).

<sup>52</sup> *Id.* (Secretary Heckler was replaced by Dr. Bowen during the litigation.).

<sup>53</sup> 729 F.2d 144 (2d Cir. 1984).

<sup>54</sup> 585 F. Supp. at 542.

<sup>55</sup> *Id.*

<sup>56</sup> *Bowen v. American Hosp. Ass'n*, 106 S. Ct. 2101 (1986).

<sup>57</sup> *Id.* at 2109.

<sup>58</sup> *Id.* at 2101.

<sup>59</sup> *Id.* at 2123 (White, J., dissenting).

<sup>60</sup> See *supra* notes 53-56 and accompanying text.

<sup>61</sup> 106 S. Ct. at 2111-12 n.11. The plurality said, "This suit is not an enforcement action, and as a consequence it is not necessary to determine whether § 504 ever applies to individual medical treatment decisions involving handicapped infants." *Id.* at 2111. The confusion lies in the Court's apparent affirmation of the Second Circuit's holding that the Secretary had no authority under § 504 to regulate infant treatment decisions. See *id.* at 2123-25 (White, J., dissenting).

the challenged final rules<sup>62</sup> were invalid.<sup>63</sup> The plurality's rationale was that parents, not hospitals, were withholding medically indicated treatment.<sup>64</sup>

The plurality found numerous proof failures in the administrative record.<sup>65</sup> First, the Secretary failed to show "that a hospital failed or refused to provide treatment to a handicapped infant for which parental consent had been given."<sup>66</sup> Second, there was no proof that hospitals discriminatorily reported parental refusal to treat normal but not handicapped infants to the appropriate state protection agency.<sup>67</sup> Third, no evidence "that physicians' predispositions against treating handicapped infants had resulted in parental refusals to consent to treatment" was present.<sup>68</sup> Because the Secretary failed to prove that discriminatory failure to treat was an actual problem, the Court found the rules to be invalid:<sup>69</sup> "In sum, there is nothing in the administrative record to justify the Secretary's belief that 'discriminatory withholding of medical care' in violation of § 504 provides any support for federal regulation . . . ."<sup>70</sup>

The plurality seems to invalidate the regulations simply because the Secretary was unable to demonstrate a clear need for government intervention. The plurality does not say specifically that the Secretary would never be authorized under section 504 to promulgate rules to prevent discriminatory treatment of handicapped infants.<sup>71</sup> As Justice White said in his dissent, the decision "[g]ives no guidance to the Secretary or the other parties as to the proper construction of the governing statute, and fails

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<sup>62</sup> See *supra* note 50.

<sup>63</sup> 106 S. Ct. at 2120-23.

<sup>64</sup> *Id.* at 2115.

<sup>65</sup> "The administrative record does not contain the reasoning and evidence that is necessary to sustain federal intervention into a historically state-administered decisional process that appears—for lack of any evidence to the contrary—to be functioning in full compliance with § 504." *Id.* at 2122.

<sup>66</sup> *Id.* at 2116.

<sup>67</sup> *Id.* at 2118. However, the plurality said, "Of course, § 504 would be violated only if the hospital failed to report medical neglect of a handicapped infant when it would report such neglect of a similarly situated nonhandicapped infant." *Id.* at n.23.

<sup>68</sup> *Id.* at n.22.

<sup>69</sup> *Id.* at 2123.

<sup>70</sup> *Id.* at 2117.

<sup>71</sup> *Id.* at 2118 n.23.

adequately to explain the precise scope of the holding . . . ."<sup>72</sup>

Arguably, the plurality decision invalidates only the four challenged rules<sup>73</sup> and leaves room for future regulation of infant care decisions. Hopefully this means that the Court has left open the possibility for future regulations under section 504.<sup>74</sup> Therefore, the *American Hospital Association* decision notwithstanding,<sup>75</sup> section 504<sup>76</sup> remains a valid mechanism for insuring that handicapped newborns are accorded nondiscriminatory treatment.

### B. Child Abuse Amendments of 1984

In response to publicity surrounding parental decisions to withhold treatment from handicapped infants in 1981<sup>77</sup> and in 1982,<sup>78</sup> the Child Abuse Amendments of 1984<sup>79</sup> included "failure to treat a handicapped infant" within the meaning of child abuse and neglect.<sup>80</sup> The Senate Report<sup>81</sup> clearly indicates that federal policy in this area prohibits withholding medically indicated<sup>82</sup>

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<sup>72</sup> *Id.* at 2132 (White, J., dissenting).

<sup>73</sup> *See supra* note 50.

<sup>74</sup> *See infra* text accompanying notes 98-99.

<sup>75</sup> 106 S. Ct. 2101.

<sup>76</sup> 29 U.S.C. § 794 (1982).

<sup>77</sup> "In May, 1981, a decision was made to withhold treatment from handicapped Siamese twins born in Danville, Illinois. Intervention by authorities resulted in a widely publicized custody battle and the filing of criminal charges against the attending physicians and the parents." SENATE COMM. ON LABOR AND HUMAN RESOURCES, CHILD ABUSE AMENDMENTS OF 1984, S. REP. No. 246, 98th Cong., 2d Sess. 4, reprinted in 1984 U.S. CODE CONG. & ADMIN. NEWS 2918, 2922.

<sup>78</sup>

In early April, 1982, a handicapped child, known to the public as "Infant Doe," was born. . . . The parents . . . made the decision to withhold medical treatment and nourishment from the child. . . . State and local courts approved the withholding of treatment and nourishment, and the infant died six days after birth while attorneys on behalf of the infant were preparing an appeal to the U.S. Supreme Court.

*Id.*

<sup>79</sup> 42 U.S.C. §§ 5101-5103 (Supp. III. 1985).

<sup>80</sup> *Id.*

<sup>81</sup> *See supra* note 77.

<sup>82</sup>

Let me stress here that some problems are simply not correctable. Some handicapped infants, unfortunately, face imminent death. For such infants it is very important to note that we do not seek to fruitlessly prolong the

treatment from disabled newborns *regardless of who makes the decision*. The report states:

Under the fundamental tenets of our society, the life of an able-bodied or disabled human being should not be brought to a premature end by parental, physician, or hospital committee decree. Where death is imminent and inevitable, and where medical intervention merely forestalls the inevitable, this Committee acknowledges that refraining from medical intervention may be an ethically and legally acceptable course. Where death is avoidable through surgical and other therapeutic means that customarily are provided to non-disabled children, however, the denial of such treatment is clearly abusive to children and is a violation of the disabled child's most fundamental rights.

Although the witnesses who testified before the subcommittee differed markedly in their views as to the appropriate response to instances of withholding treatment from severely handicapped infants, all agreed that there is a sufficient body of evidence that such cases do occur and that it is an issue that needs greater scrutiny and remedial action.<sup>83</sup>

The Act gives the Secretary of HHS the authority to promulgate implementing rules.<sup>84</sup> Final rules, published in April, 1985, require states to adopt certain definitions and procedures within their child abuse statutes to receive grants from the federal government.<sup>85</sup> The states are required to include "medical neglect"<sup>86</sup> within their definition of child abuse.<sup>87</sup> The rules define "medical neglect . . . [as] failure to provide adequate medical care"<sup>88</sup> which "includes, but is not limited to, the with-

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process of dying, rather, we seek to guarantee that infants who would live, given ordinary care, will not be denied the opportunity for life by those who would decide that their lives are not worth living.

S. REP. NO. 246, 98th Cong., 2d Sess. 4, *reprinted in* 1984 U.S. CODE CONG. & ADMIN. NEWS 2918, 2926 (quoting Dr. Everett Koop's testimony before the Subcommittee on Family and Human Services).

<sup>83</sup> *Id.* at 2928.

<sup>84</sup> 42 U.S.C. § 5102(1) (Supp. III 1985).

<sup>85</sup> 50 Fed. Reg. 14,887 (1985) (codified at 45 C.F.R. § 1340).

<sup>86</sup> 45 C.F.R. § 1340.15(b)(1) (1985).

<sup>87</sup> 45 C.F.R. § 1340.14(b) (1985).

<sup>88</sup> 45 C.F.R. § 1340.15(b)(1).

holding of medically indicated treatment from a disabled infant with a life-threatening condition."<sup>89</sup>

The term, "withholding of medically indicated treatment"<sup>90</sup> is defined as:

the failure to respond to the infant's life-threatening conditions by providing treatment (including appropriate nutrition, hydration, and medication) which, in the treating physician's . . . reasonable medical judgment, will be most likely to be effective in ameliorating or correcting all such conditions, except that the term does not include the failure to provide treatment (other than appropriate nutrition, hydration, or medication) to an infant when, in the treating physician's . . . reasonable medical judgment, (A) The infant is chronically and irreversibly comatose; (B) The provision of such treatment would merely prolong dying, not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or otherwise be futile in terms of the survival of the infant; or (C) The provision of such treatment would be virtually futile in terms of the survival of the infant and the treatment itself under the circumstances would be inhumane.<sup>91</sup>

Further, the regulations require states to establish an appropriate mechanism for responding to instances of suspected medical neglect.<sup>92</sup> The rules require each state to submit the grant application to HHS with "sufficient information and documentation to permit the Commissioner to find that the State is in compliance with the eligibility requirements"<sup>93</sup> set forth in the final rules.<sup>94</sup>

The full impact of these regulations upon treatment decisions is yet unknown. Congress, however, clearly intended the Child Abuse Amendments to prohibit the withholding of life-saving treatment from disabled infants, regardless of who makes the decision. Because the plurality in *American Hospital Association*<sup>95</sup>

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<sup>89</sup> *Id.*

<sup>90</sup> 42 U.S.C. § 5102(3) (Supp. III 1985).

<sup>91</sup> *Id.*

<sup>92</sup> 45 C.F.R. § 1340.15(c)(1)-(5).

<sup>93</sup> 45 C.F.R. § 1340.15(d)(1).

<sup>94</sup> 45 C.F.R. § 1340.15(c)(1)-(5).

<sup>95</sup> 106 S. Ct. 2101 (1986).

was influenced by the lack of legislative history to support the Secretary's action,<sup>96</sup> a similar decision probably would not be rendered in an attack on the final rules implementing the Child Abuse Amendments.<sup>97</sup> Moreover, the plurality found that the Secretary failed to prove that hospitals were withholding treatment after parental consent had been given.<sup>98</sup> This implies that, unless the Secretary is able to show proof of an institutional bias that results in differential medical treatment of handicapped and nonhandicapped infants, section 504 will not be applicable to infant treatment decisions. The plurality noted that parents were withholding treatment and private conduct is not within the purview of section 504 of the Rehabilitation Act.<sup>99</sup> In contrast, private conduct is regulated specifically under the Child Abuse Amendment of 1984.<sup>100</sup> Therefore, the amendments insure that the state's welfare agency will review all decisions to forego treatment. This should achieve the desirable result of saving the lives of infants who have medically correctable, life-threatening conditions.

## II. THE STATE'S ROLE AS DECISIONMAKER FOR HANDICAPPED INFANTS

Complete understanding of the impact of the Child Abuse Amendments of 1984<sup>101</sup> requires a review of the state's historical role in treatment decisions. Every state has a law that prohibits child abuse and neglect,<sup>102</sup> mandating that physicians report child

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<sup>96</sup> *Id.* at 2122 n.33.

<sup>97</sup> *See, e.g.*, S. REP. NO. 246, 98th Cong., 2d Sess. 4, *reprinted in* 1984 U.S. CODE CONG. & ADMIN. NEWS 2918-2928.

<sup>98</sup> *See supra* note 66 and accompanying text.

<sup>99</sup> *See supra* note 64 and accompanying text.

<sup>100</sup> 42 U.S.C. §§ 5101-5103 (Supp. III 1985). *See supra* note 83 and accompanying text. Child abuse laws are based on the assumption that the parents' right to make decisions for their child is not absolute. The state has an interest in protecting a child when his or her parents have failed to act in the child's best interest. The effect of these amendments is to include review of parental choices of medical treatment for their handicapped infant within the state's authority.

<sup>101</sup> 42 U.S.C. §§ 5101-5103 (Supp. III 1985).

<sup>102</sup> I. SLOAN, CHILD ABUSE: GOVERNING LAWS & LEGISLATION 15 (1983).

abuse.<sup>103</sup> All fifty states provide for immunity from civil or criminal action for persons making a report.<sup>104</sup> The definitions of child abuse or neglect vary from state to state.<sup>105</sup>

Even with reporting mechanisms in place, however, states traditionally have not interfered with parental decisions concerning treatment of newborns.<sup>106</sup> Perhaps this non-interference resulted because physicians rarely sought to use the mechanism to obtain a court order to treat a handicapped infant.<sup>107</sup> Further-

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<sup>103</sup> *Id.* at 22. The extent to which the statutory duty to report gives rise to civil or criminal liability is unknown. Generally, prosecutors do not file charges for failure to report cases of abuse. In *Landeros v. Flood*, 551 P.2d 389 (Cal. 1976), the court held that, if the plaintiff could prove that the physician actually saw the injuries and formed the opinion that they were intentionally inflicted, a *prima facie* case of negligence would be shown through violation of statute. *Id.* at 143.

<sup>104</sup> *Id.* at 31.

<sup>105</sup> *Id.* at 18-22. Compare GA. CODE ANN. § 26-2801(B) (Supp. 1980) ("Any person commits cruelty to children when he maliciously causes a child under the age of 18 cruel or excessive physical or mental pain.") (reprinted in I. SLOAN, PROTECTION OF ABUSED VICTIMS: STATE LAWS & DECISIONS pt. 5, at 7 (1983)) with KY. REV. STAT. ANN. § 199.011(6) (Michie/Bobbs-Merrill 1982) [hereinafter KRS].

"Abused or neglected child" means a child whose health or welfare is harmed or threatened with harm when his parent, guardian or any other person[:] . . . inflicts or allows to be inflicted upon the child, physical or mental injury to the child by other than accidental means; creates or allows to be created a risk of physical or mental injury to the child by other than accidental means; . . . does not provide the child with adequate care and supervision; food, clothing and shelter; education; or medical care necessary for the child's well-being . . . .

*Id.*

<sup>106</sup> See, e.g., *American Academy of Pediatrics v. Heckler*, 561 F. Supp. 395 (D. D.C. 1983). Judge Gesell, writing for the court, said, "Traditionally, the difficult decision of when to withhold life-sustaining treatment of a defective newborn has been one made within the privacy of the physician-patient relationship. . . . Physicians . . . frequently give great deference to the wishes of the parents who are considered guardians of the best interests of the child." *Id.* at 396. For an interesting article arguing against state intrusion into the parent's decision, see Note, *Life or Death in the Intensive Care Nursery: Who Should Decide?* 11 WM. MITCHELL L. REV. 127 (1985).

<sup>107</sup>

A great number of the physicians . . . felt that what might be a poor quality of life, in their estimation, was sufficient reason not to treat a child for a defect which may have been incompatible with life but nevertheless amendable to surgical correction. Only three percent of pediatric surgeons and 16 percent of pediatricians would seek a court order for the necessary surgery over the parents' objections, while 78 percent and 88 percent, respectively, would do so if the young child were not disabled but in need of cancer surgery.

S. REP. NO. 246, 98th Cong., 2d Sess. 4, reprinted in 1984 U.S. CODE CONG. & ADMIN. NEWS 2918, 2925 (summarizing a survey of physicians conducted in 1975).

more, when physicians have notified the appropriate protection agency, the parents' decision has been upheld as within the parents' right to choose between reasonable medical alternatives.<sup>108</sup> When court orders have been sought, courts often have denied the motions because the common law viewed parents as the best decision-makers for their minor child.<sup>109</sup> The common law appears to be out of step with prevailing beliefs and federal policy in light of the public and political outrage to the Infant Doe situation.<sup>110</sup>

The impact of the Child Abuse Amendments of 1984<sup>111</sup> and their implementing regulations<sup>112</sup> is procedural. The amendments require states to incorporate a number of safeguards within their child abuse statutes. The amendments are designed to insure that parental decisions to withhold consent for treatment will be reviewed and sometimes reversed. The states must incorporate the term "medical neglect"<sup>113</sup> within their child abuse statutes.<sup>114</sup> Once the definition is incorporated, physicians will have a statutory duty to report parental refusal of consent to treatments which are "most likely to be effective in ameliorating or correcting all [life-threatening] conditions . . . ."<sup>115</sup> Thus, the traditional approach of allowing parents and physicians<sup>116</sup> to be the final arbiters in decisions to forego treatment must be rejected by the reviewing court and state protection agency.

### CONCLUSION

The federal government continues to play an important role in prohibiting discriminatory treatment of handicapped chil-

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<sup>108</sup> The extreme example of this is in the case of Infant Doe of Bloomington, in which denial of food and water was considered a reasonable medical alternative. See Comment, *supra* note 2, at 890.

<sup>109</sup> *Id.* at 891, 894 n.29.

<sup>110</sup> See *id.* at 890.

<sup>111</sup> 42 U.S.C. §§ 5101-5103 (Supp. III 1985).

<sup>112</sup> 42 C.F.R. § 1340 (1985).

<sup>113</sup> 42 C.F.R. § 1340.15(b)(1) (1985).

<sup>114</sup> 42 C.F.R. § 1340.2(d) (1985).

<sup>115</sup> 45 C.F.R. § 1340.15(b)(2) (1985). For the parameters of those decisions to forego treatment which constitute abuse, see *supra* notes 66-67 and accompanying text.

<sup>116</sup> See, e.g., *supra* note 106.



dren.<sup>117</sup> Ironically, the impetus has come from the Child Abuse Amendments of 1984<sup>118</sup> rather than from section 504 of the Rehabilitation Act<sup>119</sup> which was patterned after the Civil Rights Act of 1964.<sup>120</sup> Fortunately, the impact on the parents' right to be the decision-makers<sup>121</sup> for their child is far more extensive than could have been achieved under the Rehabilitation Act of 1973.<sup>122</sup>

The full impact of the Child Abuse Amendments on "Baby Doe" situations will be determined by future judicial interpretations. State protection agencies and courts will have to wrestle with the difficult ethical decisions in the hard cases in which the therapeutic value of surgery is marginal. The courts now have statutory authority<sup>123</sup> to justify, and interpretive guidelines<sup>124</sup> to aid, the making of decisions to override the parents' choice to withhold treatment. Understanding the history of the "Baby

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<sup>117</sup> See Education of All Handicapped Children Act of 1975, 20 U.S.C. § 1401 (1982) (assures free and appropriate access to public education for handicapped children ages 3-21); Rehabilitation Act of 1973, 29 U.S.C. § 794 (1982) (providing nondiscriminatory access to all programs which receive federal financial assistance); Developmental Disabilities Assistance and Bill of Rights Act of 1975, 42 U.S.C. § 6010(1), (2) (1982) (insuring the right of developmentally disabled persons to receive appropriate treatment and services in the least restrictive environment).

<sup>118</sup> 42 U.S.C. §§ 5101-5103 (Supp. III 1985).

<sup>119</sup> 29 U.S.C. § 794 (1982). See *supra* note 13.

<sup>120</sup> Civil Rights Act of 1964, § 601, 42 U.S.C. § 2000(d) (1982). "No person in the United States shall, on the ground of race, color, or national origin be excluded from participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance." *Id.* See generally R. SCOTCH, FROM GOOD WILL TO CIVIL RIGHTS (1984) (an excellent comparison of the Civil Rights Act § 601 and the Rehabilitation Act § 504).

<sup>121</sup> Mathieu, *supra* note 18, at 608 n.10.

<sup>122</sup> 29 U.S.C. § 794 (1982). Section 504, by definition, is limited to prohibiting discriminatory treatment by programs that receive federal funds. *Id.* Therefore, parents are not prohibited by the act from taking into account their child's handicap when making a treatment decision. However, the Child Abuse Amendments define failure to treat as child abuse. 42 U.S.C. § 5102 (Supp. III 1985). Thus, the abusing parents' rights are no longer relevant.

<sup>123</sup> 42 U.S.C. §§ 5101-5103 (Supp. III 1985). To date, 47 states and the District of Columbia are known to be in compliance with the regulations implementing the Child Abuse Amendments. The three remaining states did not apply for grants from the federal government this year. Telephone interview with J. Olson, Program Specialist, National Center on Child Abuse and Neglect (NCCAN), (Oct. 16, 1986).

<sup>124</sup> Appendix to Part 1340—Interpretive Guidelines Regarding 45 C.F.R. § 1340.15—Services and Treatment for Disabled Infants, 45 C.F.R. Ch. XIII, 213-20 (1985).

Doe'' controversy and what the outcome says of our society's commitment to the sanctity of life should serve as guidelines for courts. As Justice Marshall wrote,

[S]hifting cultural, political, and social patterns at times come to make past practices appear inconsistent with fundamental principles upon which American society rests. . . . It is natural that evolving standards of equality come to be embodied in legislation, when that occurs, courts should look to the fact of such change as a source of guidance on evolving principles of equality . . . .<sup>125</sup>

Society has an interest in protecting the rights of disabled infants. No longer can physicians and parents choose nontreatment of a correctable condition because the child has limited potential, without being held accountable for their decision. They would do well to take Justice Marshall's advice and review the "Baby Doe" controversy for guidance in making future treatment decisions.

*Mary Ann Born*

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<sup>125</sup> City of Cleburne v. Cleburne Living Center, 105 S. Ct. 3249, 3269 (1985) (Marshall, J., dissenting).

